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Gross Motor Outcomes After Dynamic Weight-Bearing in 2 Children With Trunk Hypotonia: A Case Series

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Gross motor outcomes after dynamic weight bearing in two children with truncal hypotonia: a case series.

Short Title for Running Head: Dynamic weight bearing in truncal hypotonia

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ABSTRACT:

Purpose: Children with truncal hypotonia have limited ability to maintain an upright weight bearing position, resulting in decreased postural control and a delay in achieving gross motor milestones. The purpose of this case series was to report the impact of a home-based dynamic standing program on postural control and gross motor activity in two children with truncal hypotonia. **Summary of Key Points**: Child 1 (age 24 months, Gross Motor Function Classification Scale (GMFCS) Level IV) and Child 2 (age 21 months, GMFCS Level V) participated in a standing program using the Upsee harness at home three days per week for 12 weeks. Final testing revealed that both children improved their gross motor function, and Child 1 demonstrated improved trunk control in sitting. **Statement of Conclusions**: The use of the Upsee harness was an effective intervention for these children with truncal hypotonia to achieve weight bearing and improve gross motor abilities.

INTRODUCTION:

While hypotonia is often described as a decrease in the resistance to passive joint motion, it can also be defined as an impaired ability to maintain postural control and movement against gravity.[1] Central hypotonia results from abnormalities of the central nervous system, and can be caused by cerebral palsy or chromosomal disorders.[1] The poor postural control associated with central hypotonia limits the child's ability to interact with the environment delaying attainment of developmental milestones such as sitting, crawling, standing and walking. In addition, participation in social interactions with peers and caregivers may be restricted resulting in a decreased quality of life for these children.[2]

Supported standing programs have been used for more than 50 years to ameliorate impairments and optimize function in children with poor postural control and limited standing or walking function.[3] Supported standing has positive effects on hamstring, plantar flexor, and hip range of motion,[4,5] lower extremity tone,[6,7] base of support,[8] postural responses,[9] gross motor functional mobility,[,10] and walking function.[6] Increased electromyographic activity and postural responses while in an orthotic standing shell have been reported in a child with spina bifida.[9] Increased peer, caregiver, and social interactions,[3,11] as well as reduced burden of care[9] have all been associated with supported standing programs. In a systematic review of pediatric supported standing programs, Paleg et al.[3] suggested pairing upright posture at eye level with others with activities that foster communication and participation. In addition to passive standing devices, the authors recommended use of an active standing device that steps, vibrates, oscillates, sways, turns, bounces, and allows the user to move under their own power. Effective dosage was five days per week with duration dependent on desired outcomes; for spasticity reduction, 30-45 min/day; to increase range of motion, 45-60 min/day; for improved hip biomechanics, 60 min/day with hip abduction 30°-60°; and to improve bone mineral density, 60-90 min/day.[3]

Use of a gait trainer that provides trunk and pelvic support has been reported to improve mobility, walking function, social function, and participation in children with motor impairments.[12] The Upsee[13] (Firefly by Leckey, Lisburn, Northern Ireland) is an orthotic standing and walking device that consists of an adult hip belt, child harness, and shared sandals, which is worn by the child and parent. This device meets many of the recommendations of Paleg and colleagues,[3,12] being designed to promote adult assisted upright standing and movement by the child with peer and environment interactions at eye level. As the adult stands, moves, and walks, the child is encouraged to stand, move, and step. The child’s postural reactions are stimulated in response to weight shifting, stepping, and turns by the adult. Functional tasks and participation activities are encouraged while the child is upright in the Upsee.

The use of the Upsee to provide a dynamic standing program has not been formally studied. However, because of its simple design and ease of use, the Upsee would be an easy addition to any home program designed to increase standing and weight shifting in children. Thus, the purpose of this case series was to report the impact of a home-based dynamic standing program using the Upsee on postural control and gross motor activity in two children with truncal hypotonia.

CASE DESCRIPTIONS:

Child 1

Child 1 was a 24-month-old boy born at 37 weeks gestation and diagnosed at birth with a rare form of chromosome 3 deletion and agenesis of the callosum. The child displayed the ability to follow simple commands, however, he was unable to effectively communicate his wants and needs. Generalized hypotonicity was the primary impairment identified using the International Classification of Functioning, Disability, and Health Framework for Children and Youth model (ICF-CY).[14] His gross motor skills were equivalent to those of a typically developing 6-month-old. For example, he was able to maintain static sitting balance once placed, but was unable to transition to or from sitting independently. Also, he could roll bilaterally but could not attain quadruped or pull to stand. He was classified as Level IV using the Gross Motor Function Classification System (GMFCS).[15] He had consistently received physical therapy twice weekly in a home health setting starting at 1 month of age that continued throughout the study timeframe.

Child 2

Child 2 was a 21-month-old boy born at 39 weeks gestation. Prior to birth, his mother experienced decreased fetal movement. A cesarean section was performed and the baby was found to have a true umbilical cord knot, causing hypoxic ischemic encephalopathy. He was in the Neonatal Intensive Care Unit (NICU) for 39 days and was diagnosed with cerebral palsy (CP) at 12 months of age. Upon discharge from the NICU, the child received weekly home health physical therapy that continued throughout the study timeframe. The child displayed good receptive communication skills as demonstrated by his ability to follow 1 and 2 step commands within his movement repertoire. His expressive communication was limited to facial expressions of pleasure or displeasure. Primary impairments identified using the ICF-CY model were hypotonicity of the trunk and cervical muscles with hypertonicity at all four extremities. His GMFCS classification was Level V.

Clinical Impression

The two children included in this case series both displayed truncal hypotonicity with significant gross motor delays for their ages. They both displayed the cognitive ability to follow simple commands, however neither child had verbal communication skills. Both of these children had excellent family support and their parents were willing to implement the intervention at home in addition to attending their regular physical therapy sessions.

Outcome Measures

The parents of both children expressed an overall goal of improved functional independence. Thus, outcome measures were chosen to detect change in trunk control and gross motor function: 1) the Segmental Assessment of Trunk Control (SATCo),[16] and 2) the Gross Motor Function Measure (GMFM-66).[17]

The SATCo is a reliable and valid measure for assessing discrete levels of trunk control in children with motor disabilities.[16] For this assessment, the child is placed in short sitting on a low bench with his feet supported on the ground, and pelvis secured in a neutral position. The examiner's hands are positioned to support the child's trunk in a neutral position with normal spinal curves. The examiner's hands are then moved segmentally down the child's trunk through seven different support levels. At each level, the examiner tests the child's static, active, and reactive trunk control.[16] The SATCo score is acquired by assigning points for the type of control observed at each of the support levels with a possible total of 20 points.

The GMFM-66 has been validated for assessing gross motor function in children with cerebral palsy, and may also be used to evaluate change in gross motor function for children with similar neurological disorders whose motor skills are at or below those of a typically-developing 5-year-old child.[18] This measure consists of five dimensions: (A) Lying and Rolling, (B) Sitting, (C) Crawling and Kneeling, (D) Standing, and (E) Walking, Running, and Jumping. For each dimension a raw score is obtained and a raw total score is calculated. Marois and colleagues[19] described a new method for interpreting change in GMFM-66 scores in studies lacking a control group. These researchers developed curves that predict the natural progression of a child's motor development based upon the initial GMFM-66, age at time of evaluation, and GMFCS classification level.

Initial Assessment

Two experienced pediatric physical therapists performed the assessment at a local university in a large open room. The only materials used during testing included: a floor mat, a small table, a child-sized bench, and a few age-appropriate toys. The same two physical therapists were present at each pretest and posttest session. Neither therapist was blinded to the study design, however both therapists scored each child individually, and then compared the results. Both raters agreed on each score for every item in order to eliminate bias in testing.

Child 1

The initial SATCo score for child 1 was 11 out of 20. His initial GMFM-66 raw total score was 35, with the highest score in dimension B, and a score of 0 for dimensions D and E. At the initial assessment, the child was able to roll supine to and from prone bilaterally without assistance and could attain prone on forearms. He was also able to maintain sitting balance once placed, but required assistance to transition from supine to sitting. The child was not able to ambulate with or without an assistive device and relied on a caregiver for wheeled mobility. Initial SATCo scores and GMFM-66 individual dimension scores are presented in Table 1.

Child 2

Child 2 scored 0 out of 20 on the SATCo outcome measure. During observation of functional movements, the child was unable to fully attain prone on elbows and was unable to roll from supine to prone. He could not maintain his balance when placed in sitting on the mat. The child was non-ambulatory, and relied upon an adult pushing his wheelchair for functional mobility. His initial GMFM-66 raw total score was 16, with the highest score in dimension A, and a score of 0 for dimensions D and E (Table 1).

Description of Intervention

The parents of both children provided consent for this study. The intervention was designed as a home-based dynamic weight bearing program to be implemented in addition to weekly physical therapy sessions. Each child was provided with an Upsee harness to use with a parent at home. During the first assessment session, parents were instructed in use of the device and both parent and child were strapped into the Upsee. The harness system was adjusted by a physical therapist to provide appropriate anatomical alignment and positioning for the child to bear weight through the lower extremities (Figure 1). Before taking the Upsee home, the parent and child wore the device for 10 minutes in a standing position and practiced gentle weight shifting right and left to demonstrate understanding of proper use.

The parents were educated on dynamic weight bearing with the understanding that the child should display muscle activation in the trunk and legs while using the Upsee. They were told that a second pair of hands might sometimes be necessary to encourage this muscle activation. While in the device, the child was encouraged to extend through his trunk by looking up or forward. When the child slumped in the device or was no longer actively using his muscles, parents were instructed to stop use and try again later. They were provided a list of suggested activities that progressed from “easy” (stand at table with an activity such as playing, painting, or coloring) to “difficult” (slow walking with the child leading most of the movement). Other activities included gentle weight shifts in an open area (Appendix 1).

The children’s parents were asked to use the harness four days per week over the course of 12 weeks with no other changes to their child’s routine. The initial goal was at least one active Upsee session of 2 minutes per day, progressing to 20-30 minute sessions per day. The parents were asked to journal the amount of time spent in the device and activities performed by their child (Appendix 2). Home health physical therapy continued weekly as before. The parents reported use of the device in their homes and occasionally outside in the yard.

OUTCOMES:

Child 1

The parents of Child 1 reported consistent use of the harness upright mobility system for an average of 3.64 days per week over the course of the intervention period, with no instances of adverse events. Time spent in the harness system ranged from 10 minutes initially, and gradually increased to 35 minutes as the child became accustomed to the harness system. The average time spent in the harness was 21.18 minutes per session, with a total time over the study period of 847 minutes. See Appendix 2 for a detailed description of the frequency, duration, and activities performed during the intervention.

This child demonstrated improved gross motor ability, evidenced by an increased score on the GMFM-66 from an initial total score of 35 to a score of 42. He achieved functional gains across all five dimensions (Table 1). Additionally, the child demonstrated improvement in his trunk control, increasing his SATCo score from 11/20 to 20/20, with the greatest improvements in lower lumbar and full trunk control (Table 1).

At the end of the study timeframe, the parents also reported positive changes in the child's interactions at home. His mother stated that he could walk with bilateral hand held support and he began taking steps independently with a gait trainer in physical therapy. Additionally, she noted improvements in her child's head control, including the ability to maintain an upright head posture for longer periods of time during meals. Improved head control also allowed the child to interact more with both parents and siblings. Shortly after the end of the intervention, the child began using simple sign language to express himself.

Child 2

Child 2 used the intervention for an average of 3.92 days per week over the course of 12 weeks, with no instances of adverse events. Initially, the child spent 10 minutes in the upright mobility harness system, with more time spent statically standing. The time was gradually increased and by the end of the study, the child was able to tolerate 15 minutes in the harness with more time walking, which was initiated by the child himself. The child was unable to tolerate periods longer than 15 minutes due to poor head control. The average time spent in the harness was 12.08 minutes per session, and the total amount of time over the study period was 568 minutes. Appendix 2 summarizes the parents' reported use of the intervention.

Child 2 also demonstrated improved gross motor ability, as demonstrated by an increased GMFM-66 score from an initial total score of 16 to a score of 21. This improvement represented gains in four out of the five dimensions (Table 1). Although this child did not demonstrate advances with trunk control, his mother reported improvement with upright head control during feeding and gross motor activities. This child also gained the ability to independently take steps with a gait trainer in physical therapy. The child enjoyed being in the Upsee and his mother asked to keep it longer. After the intervention period ended, the child was able to participate as a ring bearer in a relative's wedding by walking with his mother down the aisle in the Upsee. He maintained his head up for most of the walk down the aisle, smiling as he went.

DISCUSSION:

Children with truncal hypotonia can participate in, and may benefit from, a dynamic standing program. This case series of a home-based intervention utilized a new device, the Upsee, and was implemented under the direction of two skilled pediatric physical therapists with full participation of the children's parents. Neither child experienced adverse events while using the Upsee, as the parents of both children closely followed the usage guidelines and progression protocol provided by the study authors. Based on the improvements observed, we speculate that this program may be an effective and safe way to improve gross motor abilities of children with severely impaired postural control.

Both children in this case series demonstrated improved gross motor development during the period in which they used the Upsee device. On the GMFM-66, Child 1 improved by seven points, and Child 2 increased his score by six points. Using the prediction curves developed by Marois et al.,[19] over the three-month intervention period the expected natural evolution for Child 1 was 2.11 points, and for Child 2 was 1.41 points. The changes demonstrated by both children exceeded these predictions.

Despite these improvements in the GMFM-66, only Child 1 demonstrated improved trunk control as measured by the SATCo. This child, who initially could only maintain postural control when sitting with support at his lower ribs, was able to maintain reactive postural control in sitting without support by the end of the study period. Conversely, there was no change in trunk control as measured by the SATCo in Child 2.

There was a vast difference in the intervention dosage for each child. Child 2 spent less time overall in the Upsee harness, and never progressed beyond 15 minutes of weight bearing per session. Paleg et al.[3] suggest that children need 30 to 60 minutes of standing to achieve certain desired outcomes, such as decreased spasticity, increased range of motion, and increased bone mineral density. Recommendations for dosage to improve trunk control do not yet exist in the literature. Given the outcomes of the two children in our case series, we suspect that at least 20 to 30 minutes three times a week of dynamic standing may be needed to improve trunk control in children with truncal hypotonia.

The use of the Upsee at home three to four days per week was in addition to both children's typical home based physical therapy program conducted two times per week. During the home-based therapy sessions, the children continued to work on non-weight bearing gross motor activities in supine, prone, and sitting positions. Heathcock et al.[20] reported that children with higher GMFCS levels may benefit from daily, intensive therapy. We surmise that the increased frequency of gross motor activity afforded by the addition of Upsee training may have also contributed to improved functional outcomes. While our intervention was not performed directly by a physical therapist, the children's standing program was designed and progressed by a physical therapist. The children in our case series made similar gains to those observed in the Heathcock[20] study, demonstrating that children with lower functional abilities benefit from an increased frequency in gross motor activities.

In addition to the changes gained on measurable outcome tools, the parents of both children reported positive changes in mobility and social participation. Both children in this case series were actively engaged while standing in the Upsee. The parents reported that the children would often smile, laugh, and request to do certain activities while suspended in the device. Child 1 loved to sweep the floor or kick a ball, and Child 2 went for frequent walks outside. Furthermore, by the end of the study period, both children were able to take steps independently with a gait trainer. This new functional ability created a new avenue for physical therapy goals and interventions for both children. Their increased participation in their community suggests an improved quality of life.

Limitations:

The frequency of the intervention implementation was dependent upon the availability of the children's parents. While both families were motivated to participate, neither family was able to utilize the Upsee harness four days a week consistently. Although the children did show improvements, we do not know if these changes would have been greater had the frequency of standing been increased.

As stated previously, both children continued to attend their traditional physical therapy program throughout the study period. Therefore, the gains made during this time cannot be solely attributed to the upright dynamic weight bearing protocol. However, the gains attained during the study period were more rapid than the gradual gains each child had made over the previous 12 month period in traditional physical therapy, as reported by the children's parents.

Future Research:

As this report is a case series, future research is needed to further explore the effective dosage of an upright dynamic weight bearing program for children with impaired postural control. Studies with a more homogenous and larger sample are needed to conduct a randomized controlled trial design comparing the use of the Upsee to a traditional standing frame. Future studies should also aim to capture changes across the full ICF-CY model, including activities and participation.

CONCLUSIONS:

The findings from this case series support the use of the Upsee to provide a home-based upright dynamic weight bearing program for children with impaired postural control. The positive changes observed in gross motor skills suggest the need for larger studies in a more homogenous population.

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Appendix 1: Parameters for use of the harness system

Upsee Study Protocol

- When child is in the Upsee, the muscles in his trunk and legs should be active.
- Initially, a second pair of hands may be necessary to encourage trunk and leg muscle activation.
- Encourage child to extend his head and neck by looking forward or up.
- If you feel child "slumping" or sliding down while upright in the Upsee, stop use and try again later.
- Initially, aim for at least one active Upsee session of 2 minutes per day, working up to 20-30 minute sessions per day.
- Perform Upsee sessions of any length at least 4 x per week, documenting time of each session and activities performed.
- Progress through the following activities, starting from the top and working down, as tolerated:
    1. Stand at table with activity (playing, painting, coloring, etc.)
    2. Stand in open area and begin weight shifting slowly side to side
    3. Stand in open area and weight shift in staggered stance forward/ back
    4. Initiate stepping movement slowly until you feel child "takeover"
    5. Slow walking with child leading most of the movement

Appendix 2: Summary of frequency of harness system use.

Child 1			
Week	Day	Time Spent in Harness	Activity performed in Harness
1	1	10 minutes	Standing
	2	10 minutes	Standing with pillow posterior
	3	10 minutes	Standing
	4	15 minutes	Standing/ swaying
	5	15 minutes	
2	1	20 minutes	Standing/ swaying
	2	17 minutes	Standing/ walking
	3	20 minutes	Standing/ walking
3	1	20 minutes	Standing/ walking
	2	20 minutes	Standing/ swaying
4	1	20 minutes	Standing/ swaying
	2	20 minutes	Standing/ swaying
	3	20 minutes	Standing/ swaying/ squats
	4	25 minutes	Standing/ dancing
5	1	15 minutes	Standing
	2	15 minutes	Standing/ swaying
	3	25 minutes	Standing
	4	25 minutes	Standing/ swaying
6	1	20 minutes	Standing/ swaying
	2	20 minutes	Standing/ swaying
	3	15 minutes	Standing/ swaying
7	1	20 minutes	Standing/ walking
	2	25 minutes	Swaying/ walking
	3	25 minutes	Swaying/ walking
8	1	15 minutes	Rocking/ walking
	2	25 minutes	Swaying/ walking
	3	20 minutes	Swaying/ walking
	4	20 minutes	Swaying/ walking/ soccer
9	1	25 minutes	Standing/ walking
	2	20 minutes	Walking/ soccer/ dancing
	3	20 minutes	Standing/ walking
	4	25 minutes	Standing/ walking
10	1	35 minutes	Standing/ walking
	2	30 minutes	Standing/ walking
	3	35 minutes	Standing/ walking
	4	30 minutes	Standing/ walking
11	1	25 minutes	Standing/ walking

	2	25 minutes	Standing/ walking
	3	20 minutes	Walking/ kicking
	4	30 minutes	Standing/ walking/ dancing

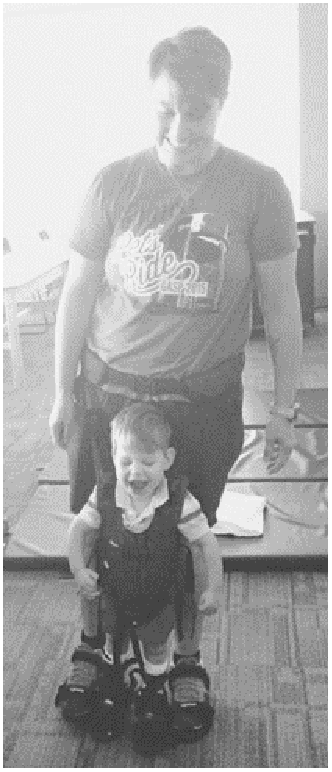
Child 2			
Week	Day	Time Spent in Harness	Activity performed in Harness
1	1	10 minutes	Standing/ swaying
	2	10 minutes	Standing/ swaying/ walking
	3	10 minutes	Standing/ swaying/ walking
	4	10 minutes	Standing/ swaying/ walking
	5	10 minutes	Standing/ swaying/ walking
2	1	10 minutes	Standing/ swaying/ walking
	2	10 minutes	Standing/ swaying/ walking
	3	10 minutes	Standing/ swaying/ walking
	4	10 minutes	Standing/ swaying/ walking
	5	15 minutes	Standing/ swaying/ walking
3	1	10 minutes	Standing/ swaying/ walking
	2	10 minutes	Standing/ swaying/ walking
	3	10 minutes	Standing/ swaying/ walking
	4	8 minutes	Standing/ swaying/ walking
4	1	10 minutes	Standing/ swaying/ walking
	2	10 minutes	Standing/ swaying/ walking
	3	10 minutes	Standing/ swaying/ walking
	4	10 minutes	Standing/ swaying/ walking
5	1	10 minutes	Standing/ swaying/ walking
	2	10 minutes	Standing/ swaying/ walking
	3	10 minutes	Standing/ swaying/ walking
	4	10 minutes	Standing/ swaying/ walking
	5	15 minutes	Standing/ swaying/ walking
	6	15 minutes	Standing/ swaying/ walking
6	1	10 minutes	Standing/ swaying/ walking
	2	10 minutes	Standing/ swaying/ walking
	3	15 minutes	Standing/ swaying/ walking
7	1	15 minutes	Standing/ swaying/ walking
	2	15 minutes	Standing/ swaying/ walking
	3	15 minutes	Standing/ swaying/ walking
	4	15 minutes	Standing/ swaying/ walking
8	1	15 minutes	Standing/ swaying/ walking
	2	15 minutes	Standing/ swaying/ walking
	3	15 minutes	Standing/ swaying/ walking
	4	10 minutes	Standing/ swaying/ walking

9	1	15 minutes	Standing/ swaying/ walking
	2	15 minutes	Standing/ swaying/ walking
10	1	10 minutes	Standing/ swaying/ walking
	2	10 minutes	Walking
	3	15 minutes	Standing/ swaying/ walking
11	1	15 minutes	Standing/ swaying/ walking
	2	15 minutes	Standing/ swaying/ walking
	3	15 minutes	Standing/ swaying/ walking
12	1	15 minutes	Standing/ swaying/ walking
	2	15 minutes	Standing/ swaying/ walking
	3	15 minutes	Standing/ swaying/ walking
	4	10 minutes	Standing/ walking

Figure Legend:

Figure 1: Child and parent initial fitting of the Upsee harness system.

Figure 1



Table

Table 1: Results of outcome measures at initial and post intervention

Outcome Measure	Child 1				Child 2			
	Pre-test	Post-test	Actual change	Expected change*	Pre-test	Post-test	Actual change	Expected change*
GMFM-66								
A. Lying & Rolling	12	12			10	11		
B. Sitting	23	24			5	8		
C. Crawling & Kneeling	0	2			1	1		
D. Standing	0	1			0	1		
E. Walking, Running, & Jumping	0	3			0	1		
Total GMFM-66 Score	35	42	7.0	2.11	16	22	6.0	1.41
SATCo	11/20	20/20			0/20	0/20		

GMFM= Gross Motor Function Measure-66
SATCo= Segmental Assessment of Trunk Control
*As predicted by Marios et al.[19]